

DEBATE

One principle and a fourth fallacy of disability studies

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This brief paper shows that the idea of benefits to the subject compensating for the harms of disability is at best self defeating and at worst sinister. Equally benefits to third parties while real are dubious as compensating factors. This shows that disabilities are just that, a net loss and not a net gain.

I feel privileged to have taken part in this symposium and to have had the benefit of this exchange with Tom Koch. However, his clarification raises more problems than it solves.¹ Koch suggests that Steven Hawking's condition may have contributed positively to his work; that may well be true but what follows? The lessons Koch believes we may learn are clearer from two comments Koch makes. First he suggests, "'harm' (resulting from a distinguishing condition) is balanced, and in some cases outweighed, by the resulting 'benefit'." What does "balanced" mean here—does it mean that overall the disability is worth having for the good that it does? If it does not mean this what does it mean? If Koch's remarks are taken at face value it might be right to inflict such a condition—for example on children for the sake of the balancing good, rather in the way that I balance the pain and inconvenience of surgery against the resulting good both for myself and my children. This looks as though it means that the disability is somehow acceptable or justified by the balancing good. It seems close to saying that suffering is balanced by the character-improving qualities that it has. But if the benefit of disability can balance the harm then it can over-balance it, and it could be true that one legitimate way to achieve those goods might be to *impose* the suffering or the disability on children for the sake of the benefit. Or to make a weaker claim, to say that the disability or suffering doesn't matter because of the good that it brings. Of course someone with Motor Neurone Disease could, in the event of a cure being found, freely choose to remain as he is for the sake of the benefits to his work, but it is quite another thing to choose to impose disease on a child in the expectation both of compensating Hawking-like benefits and in the expectation that this new individual will make the same cost benefit analysis. If Koch is serious and if we care that our children have all the benefits we can provide then this might surely be not only right but mandatory.

If "harm" resulting from a distinguishing condition may be balanced by a good or benefit, that seems to imply something else, namely that the

good or benefit could be adequate compensation for the condition. Suppose there is someone who, through fault of another, has been disabled. A court might decide, following Koch, that she had no claim for compensation because the condition had already been compensated for by the balancing benefit. If "balance" here doesn't mean that this is both possible and possibly legitimate, what does it mean?

Secondly, Koch takes a different tack, he talks about the benefits to family members (and presumably friends) of persons with these "life-enhancing conditions". When Koch says: "in these cases the experience (of harm) is formative and in some cases positively transforming" I must confess I feel a distinct chill. How are we to think of these formative and positively transforming benefits derived from other people's illness? I have no objection to people making the best of a bad job, but we mustn't lose sight of the fact that it really is a very bad job that we are talking about. Remember the context of the symposium, which gave rise to this exchange. It was primarily about the desirability of preventing and curing disease and disability, about whether what people like me term "disabilities" are really bad at all and as Koch terms it, about "the protection of persons of difference". In that context, if disabilities are harms to the individuals who suffer (sorry!) from them then the "secondary gain" of others from the illness is surely a highly problematic compensating factor. It implies that somehow the harm of the disease is mitigated by factors such as these and that it might conceivably be right to decline to prevent or cure the disease or disability for fear of losing these "positively transforming" benefits for the friends and relatives. That is not, of course, to say that *no* benefits to third parties would justify refusal to protect from disability. But such benefits would have to be massive, urgent, and unobtainable by other more moral means. Here, surely, the beneficial "feel good factors" could not conceivably be of sufficient weight or urgency and are in any event obtainable by other means.

Of course if "disabilities" are really only "physically or cognitively distinguishing features" as Koch claims then it might well look as though such secondary gain is well worthwhile. And if they are, as Koch quotes a Canadian jurist as claiming, a "life enhancing condition", then how could it possibly be wrong to confer such a benefit on children even without the various forms of secondary gain?

REFERENCE

- 1 Koch T. One principle and three fallacies of disability studies. *Journal of Medical Ethics* 2002;28:203.

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